



NATIONAL ALLIANCE FOR
THROMBOSIS & THROMBOPHILIA

Stop The Clot®

First Tuesday

DECEMBER 17, 2009

*To prevent, diagnose and treat thrombosis and thrombophilia
through research, education, support and advocacy*

Please note that First Tuesday will be on vacation in January and will be back in February!

CALL TO ACTION – DECEMBER 31 DEADLINE:

SPEAK OUT ON GOVERNMENT POLICY AND BLOOD CLOTS!

YOU TOO CAN WEIGH IN ON HEALTHY PEOPLE 2020

“Blood clots and clotting disorders have never been included in the 'Healthy People' priorities since the U.S. Department of Health and Human Services (DHHS) began assembling public health objectives for each decade beginning in 1990,” according to NATT’s CEO Alan Brownstein. NATT President Randy Fenninger said, “We are launching a nationwide campaign to make sure that it is included as a priority for the decade ahead. If we succeed, this will pave the way for increased funding for research, education and programs of prevention at the federal level. This will surely lead to saving more lives in the years ahead.”

“Healthy People” guides policy on health priorities decade by decade. Blood clots/clotting disorders are included in the initial draft, thanks to the leadership of federal health agencies with NATT’s participation.

The two blood clots–related objectives in the “Healthy People 2020” draft are:

- 1) reduce the proportion of adults who develop venous thromboembolism (VTE*) during hospitalization;**
- 2) reduce the proportion of persons who develop venous thromboembolism (VTE*).**

*[*VTE is the “umbrella” term for DVT or PE (leg or lung clot)]*

ACT NOW – WE NEED YOUR SUPPORT

We need to make sure that blood clots are included in the final Healthy People 2020 document. The blood clot/clotting disorders community of patients, family members and health professionals must act now to make sure that **preventing blood clots is included** in Healthy People 2020. To find out what you can do as NATT leaders and friends [\[CLICK HERE\]](#).

ISAACS TESTIFIES FOR DVT/PE INCLUSION IN HEALTHY PEOPLE 2020



Joseph Isaacs, an expert in health policy, represented NATT at a Healthy People 2020 Public Meeting on November 7, 2009 in Philadelphia. Healthy People 2020 provides a framework for setting federal public health objectives and priorities through 2020. Neither blood clots nor clotting disorders have ever been identified as national priorities in the past. Isaacs represented NATT last June as a member of a working group comprised of federal agencies seeking to develop language that includes blood disorders for Healthy People 2020. The result was a draft that included two objectives: reducing VTE during

hospitalization; and reducing the proportion of persons who develop VTE (see call to action above). Joe presented a powerful statement representing NATT's position in support of these objectives. [\[CLICK HERE\]](#) to read Joe's full statement. In 2010, the objectives adopted by Healthy People 2020 will be released. In 2008, Joe had two DVTs after undergoing knee surgery.

NATT'S YOUTUBE CHANNEL LAUNCHED WITH NATT-MN STOP THE CLOT® FORUM*



This is **Mark Reding, MD** (Director of the Center for Bleeding and Clotting Disorders, University of Minnesota) in one of his eight installments on **"Everything You Ever Wanted to Know About Blood Clots"** from the Minnesota Stop the Clot® Forum last fall. There will be five additional bi-weekly installments through the end of February. The full schedule of YouTube programming for this NATT-MN Forum is listed below. In addition to our YouTube channel, there will be access from our web site [\[Click Here\]](#). The

theme of the overall program was "Thrombosis & Thrombophilia: The New Frontier in Public Health", and was produced as part of a Cooperative Agreement with The Centers for Disease Control and Prevention (CDC). The Minnesota Chapter of NATT (NATT-MN) presented this comprehensive Stop the Clot® Forum to address the key issues faced by patients and families affected by blood clots and clotting disorders.

STOP THE CLOT® FORUM VIDEO SERIES

1. **January 13, 2010:** "Women's Issues with Blood Clotting" Colleen T. Morton, MD, Hematology and Oncology HealthPartners Regions Hospital and HealthPartners Riverside
2. **January 27, 2010:** "Complications After a Clot: Rehab Strategies" Marie Christine Leisz, DO, Sister Kinney Institute, Allina Hospital
3. **February 10, 2010:** "The Voices of Experience: A Panel of Patients Living with Blood Clots" Lisa Boyd, Dale Hammerschmidt, MD, Pam Pariana, Carl Cadwallader
4. **February 24, 2010:** "A Patient's Perspective and Launching a Support Group" Pat Koppa, MPH, Public Health Consultants, LLC

All installments will be available on NATT's new YouTube channel [\[CLICK HERE\]](#). All segments will be available on NATT's new YouTube channel and archived on NATT's website, under "Learn More" and will be available "on demand." NATT CEO Alan P. Brownstein said that "the patient and medical leadership of NATT-MN produced this excellent educational program that will benefit hundreds of thousands of patients and family members across the United States."

The excellent video production for these programs was done by REM Video & Event Company, St. Louis Park, Minnesota.

GRANT AWARDS TO NATT

I am very proud to announce that NATT received two grant awards in support of our programs.

1. **Fairview Health Services** in the amount of \$3,500 for NATT-MN for patient education and assistance
2. **The John J. McDonnell Margaret T. O'Brien Foundation** in the amount of \$5,000

2009 AUDIT DOCUMENTS NATT'S GROWTH

In November, the NATT board adopted our FY2009 audit for the period ended June 30, 2009. Aside from the most important matter of receiving a clean opinion letter from Brooks, Harrison Company, LLC, the audit clearly documents NATT's growth between 2008 and 2009. In 2008, total revenue was \$580,296 in contrast with 2009 revenue of \$1,118,908 – a 92% increase! 94% of our expenditures support programs and only 6% support fundraising, management & general. Of course, this audit does not capture the dollar value of the enormous amount of time put in by NATT's chapter and national board leaders and volunteers nationwide. Our audit is available on our website: [\[CLICK HERE\]](#).

MASAB MEETS IN NEW ORLEANS



L to R: Bruce Evatt MD, Stephan Moll, MD, Jeffrey Weitz, Alan Brownstein, MPH, Craig Kessler, MD, Ken Mann, PhD, John Heit, MD, Jack Ansell, MD (Chair), Ken Bauer. Camera Shy: Andra James, MD, Ed Libby, MD, Marilyn Manco-Johnson, MD, David Garcia

On Sunday, December 6 at 6:30 a.m., the MASAB meeting was called to order by **Jack Ansell, MD**. The two and a half hour meeting focused on MASAB organization including recruitment of new members, disclosure of potential conflicts of interest, development of a formal charter and alliances with the ACForum and HTRS. There was a discussion about NATT's CDC cooperative agreement and our public awareness patient and physician surveys that are being conducted with support from **Ortho-McNeil**. MASAB commended CDC and NHLBI for their leadership in organizing the first ever National Conference on Blood Disorders in Public Health. The NATT board will consider a MASAB

recommendation calling for adding "Blood Disorders" to the name for the National Center for Birth Defects and Developmental Disabilities at CDC.

NATT NEWSLETTER FOCUSES ON CANCER AND BLOOD CLOTS*

The new NATT newsletter is out! Our thanks to **Lynn Levitt** for her tireless efforts. This issue sheds light on the risks of blood clots associated with cancer. The quality of this newsletter is directly attributed to the contributions of **Hope Galley** and **Dr. Raj Kasthuri**, as well as the Q&A from **Liz Varga** capturing the concerns of many patients. This newsletter would not have been possible without the unrestricted educational grant from **Eisai**. To read or download the newsletter [\[CLICK HERE\]](#).

A FIB ADVISORY BOARD

I was pleased to be invited by **Boehringer Ingelheim** to represent NATT on a national Atrial Fib (A Fib) advisory board which met on November 11 in Washington, DC. The board was made up of a number of A Fib patient advocacy groups, voluntary health organizations and professional societies. NATT has a unique role with this group as we are totally focused on the anticoagulation management aspects of A Fib rather than heart beat irregularities. I am looking forward to working with advisory board members so that NATT can provide information about anticoagulation to patients and relatives of those affected by Atrial Fib. This is in keeping with MASAB and NATT boards' action last year to expand the scope of our support to Atrial Fib patients with respect to anticoagulation. Towards that end, I am working with NATT volunteer and health education specialist **Anu Hosangadi** in developing a program and proposal to bolster NATT's capacity serve in this area.

MEETING WITH HRSA AND NHLBI LEADERSHIP

On November 12, 2009, I had the opportunity to meet with leadership from the Health Resources and Services Administration (HRSA) and the National Heart Lung and Blood Institute (NHLBI).

HRSA. I had a NATT/HRSA introductory meeting with **Michele Lloyd-Puryear, PhD** and **Sara Copland, MD**, Maternal and Child Health Bureau (MCHB/HRSA). MCHB has primary responsibility for the hemophilia treatment center(HTC) program. The focus of our discussion was to explore further expansion of HTCs into thrombophilia/thrombosis, as well as the potential use of 340(b) funds for that purpose.

NHLBI. I had a NATT/NHLBI introductory meeting with **W. Keith Hoots, MD**, (Director, Division of Blood Diseases and Resources). We discussed his plans to develop research priorities and ways in which we could work together in promoting optimal care for preventing DVT/PE.

Randy Fenninger was scheduled but was unable to due to an urgent matter that required him to be in California that day.

DAVID HENRY – POST-OP REHAB

After brain surgery last week, NATT Treasurer David Henry is in good spirits and is aggressively pursuing follow-up rehab and treatment. All are welcome to go to www.caringbridge.org and visit David's web site and go to the guestbook and leave David a message. David and Michele – you are in our thoughts and prayers.

AHRQ ISSUES VIDEO AND BROCHURE ON TAKING BLOOD THINNERS*

FREE DVDs FROM NATT

The HHS Agency for Healthcare Research and Quality (AHRQ) issued excellent educational videos and booklets in English and Spanish directed at new patients who are on blood thinners as well as existing patients. **Jack Ansell, MD**, Chair of NATT's Medical and Scientific Advisory Board said, "If you've recently been prescribed blood-thinning pills, such as Warfarin, you probably have a lot of questions. This video and booklet will answer many of the questions and concerns you may have about the drug. You will also learn how to fit it into your lifestyle." To view the video and to download a copy of the booklet in English or Spanish, [\[CLICK HERE\]](#). If you wish to have you own copy you can contact NATT by e-mailing: fgriffiths@stoptheclot.org for a free AHRQ DVD.



STEPHIE DAVIS STEPS DOWN FROM BOARD

After years of service on the NATT board, **Stephie Davis** recently announced her resignation. Stephie made important contributions in helping NATT put together its first development plan and in organizing a Stop the Clot® Forum in Baltimore, MD. Stephie made it clear that her commitment to NATT continues and would be available for more limited well defined responsibilities. I am pleased to report that in a discussion I had with Stephie, she agreed to work with NATT in providing initial triage with individuals around the country seeking to contribute their time on NATT projects.

LOOKING FOR TAX DEDUCTIONS?

We are now in the final weeks of NATT's year-end campaign. As the 2009 tax year comes to a close, please think about NATT on December 31 when you make your final decisions regarding charitable donations.

LAST MINUTE SHOPPING? SHOP TO STOP THE CLOT®

Please visit: www.GoodShop.com. A percentage of your last minute holiday purchases will go to NATT – it's just that simple! And, remember to SHOP to Stop the Clot® year-round for all of your online shopping needs.

NATT-MN 2010 CALENDARS

NATT-MN published calendars for 2010 featuring patient stories. I purchased a few and found them to be great for gift-giving with a message. To purchase these great gifts, [CLICK HERE](#).

NATT JOINS COALITION CALLING FOR IMPLEMENTATION OF GINA

The Genetic Information Nondiscrimination Act was signed into law May 2008, with scheduled implementation for December 7, 2009. When GINA becomes effective, there will be protection against genetic discrimination by health insurers and employers. In signing the coalition letter on behalf of NATT, president, Randy Fenninger stated that "this coalition is important to prevent any delay in implementation or any dilution of the law's impact."

FENNINGER AND NATT SUPPORT THANKSGIVING AS "FAMILY HEALTH HISTORY DAY"

NATT President Randy Fenninger stated that "we certainly appreciate that our new **Surgeon General, Regina M. Benjamin** declared Thanksgiving Day 2009 as Family Health History Day." See link for Surgeon General Benjamin's statement: [Surgeon General Declares Thanksgiving as "Family Health History Day"](#). Family history is so important for understanding our potential risk for blood clots. You can find the Office of the Surgeon General's *My Family Health Portrait* Web site at <https://familyhistory.hhs.gov>.

HEALTH CARE DELIVERY LESSON

On November 16, NATT Board member **Traci Wilkes** provided her own unique version of health care delivery with the following excellent outcome measure: **Zoe Evelyn Smith**; 5:16 pm; 6 lbs, 1.7 ounces. Congratulations Traci and Charles!

PERISCOPE

Staff Retreat	January 28-30, 2010	Tarrytown, NY
Board Strategic Planning Retreat	January 29-31, 2010	Tarrytown, NY
Women's Expo (NATT Booth #507)	January 29-31, 2010	Minneapolis Convention Center for more information CLICK HERE
NATT-MN Stop the Clot® Forum	March 6, 2010	Maplewood Community Center

Maplewood, MN

National Conference on Blood Disorders in Public Health

March 9-11, 2010

Atlanta, GA
[\[CLICK HERE\]](#)

2010 HTRS/NASCOLA Scientific Symposium

April 15-17, 2010

Chicago, IL
[\[CLICK HERE\]](#)

NATT-MN Fundraising Dinner

April 29, 2010

Chateau Lamothe, Burnsville, MN

Stop the Clot® Walk Pilot

May 15, 2010

Centennial Lakes, Edina, MN

Best regards,



abrownstein@stoptheclot.org

**These activities are conducted in cooperation with the Centers for Disease Control and Prevention (CDC).*

